



National Cancer Action Team
Part of the National Cancer Programme

The case for supported user involvement in cancer commissioning

In partnership with

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CANCER SUPPORT**

in partnership with

Users are involved in services in two main ways

“no decision about me without me”

- Choice
- Personalisation
- Experience surveys

“no decision about us without us”

- LINks/Local HealthWatch
- Cross-service involvement
- Condition-specific involvement

What is user involvement?

Users can and should be:

- Involved in managing their own condition – through self-care, choice etc
- Involved as partners in their clinical care
- Asked to provide feedback on their experience of services – through focus groups, surveys, audits etc
- Representing patient and lay views on committees
- **Engaged as partners in informing NHS services and supported in doing so**

Effective user involvement needs to be supported

- Enabling users to contribute more than their own story
- Ensuring feedback is constructive, relevant and realistic
- Enlisting and applying patient and carer experiences to explain data
- Equipping users to engage with others on behalf of commissioners
- Otherwise it is of limited value and only the loudest voices are heard

There is a strong case for disease-specific as well as pan-disease user involvement

Disease-specific user-involvement

provides insight into cancer-specific issues, e.g. specialist surgery, radiotherapy, chemotherapy

Pan-disease user-involvement
provides insight into universal issues, e.g. access to primary care; car parking charges; financial advice; A&E

Cancer Networks and cancer charities already support groups of trained service users and can engage with service users on behalf of commissioners.

Question: Why should users be involved in commissioning?

Because the only person who directly experiences the whole pathway across primary, secondary and tertiary care is the patient

Scale and complexity of cancer

around **250,000** people each year are diagnosed...

with over **200** different forms of cancer ranging from long term conditions to acute disease...

and there are now **1.8 million** people living with cancer in England...

the Government is committed to saving **5,000 lives** a year by 2014/15...

and the NHS will need to save approximately **£1.2 billion** from the cost of existing cancer services

Service users can help commissioners identify what matters most to patients

- Why some services use resources inefficiently by failing to meet fully the needs of their target group
- Why some services fail to reach their intended beneficiaries
- How re-structuring or re-configuring services can improve outcomes, reduce costs and improve patient experience

Effective cancer-specific user involvement

Active engagement between commissioners and users, enabling users to play a meaningful part in designing, delivering and evaluating cancer services to improve cancer outcomes and care

What user involvement will deliver

1. User involvement helps us to **work smarter**, cancer outcomes and patients' experience improve when users identify where to focus resource

User involvement to work smarter

Case study: Improving uptake and 'did not attends' at breast cancer screening in Newham

- **The challenge:** The mortality rate from breast cancer is higher amongst the Pakistani community than for white counterparts, although prevalence is lower. There was evidence in Newham that there was very low uptake of breast screening appointments amongst Pakistani women and these women also present to GPs at later stages
- **The user insight:** This issue was discussed at the Better Health and Wellbeing Local Action Partnership Board and also at the LINK Leadership Board where it was identified that most of the women *"did not want to be naked in front of strangers"*. This was combined with a concern that the screening staff are rarely all women and that there may be male clinicians present. It was also identified that women are often very busy looking after their family and do not put their own health first, and that *"when you see the word 'cancer' in the letter, it is shocking and you say it is not for me"*
- **The change:**
 - NHS Breast Screening appointment letters now make the point that breast screening staff are all women
 - Targeted breast screening promotion and publicity to attract women who normally do not attend screening appointments
 - Language support is available at appointments
 - A pilot project was set up by NHS Newham to improve uptake of breast screening through telephone call reminders to women new to screening prior to appointments and to those women who do not attend appointments. Calls were made in a range of community languages
- **The result:** The overall uptake of screening increased by 16%

What user involvement will deliver

2. Effective cancer user involvement can give us new insights, enabling us to ***focus on the issues which matter most to patients***

User involvement to focus on the issues which matter most

Case study: Reconfiguring oesophago-gastric services in Merseyside and Cheshire Cancer Network and North Wales Cancer Network

- **The challenge:** Oesophago-gastric cancer surgery had been spread across eight hospitals in Merseyside and Cheshire, and a further three in North Wales. In response to NICE guidance, the surgical teams were reconfigured around just three specialist centres: two in Merseyside and one covering Cheshire and North Wales. Three hospital trusts expressed an interest in hosting the centre for Cheshire and North Wales and so, on behalf of commissioners, the Merseyside and Cheshire Cancer Network undertook a review
- **The user insight:** Two service users were recruited from the MCCN and North Wales partnership groups and involved from the beginning in the review panel. The two users played slightly different roles in the review and implementation process. One user focused on the more 'big picture' strategic issues. The second service user focused on issues about inclusivity, in particular (but not limited to) ensuring appropriate travel access for those in rural areas, and support for those for whom English was not a first language (Welsh speakers as well as black and minority ethnic communities)
- **The change:** the hub site was identified and the reconfiguration was effectively managed. Service users were instrumental in ensuring that patients had equitable access to diagnostic services, specifically PET-CT scans, irrespective of whether they lived in England or Wales and that the heat was taken out of the process of restructuring
- **The result:**
 - Public, patient and clinical buy-in for change
 - Compliance with NICE Improving Outcomes Guidance
 - Patient choice protected
 - Issues relating to travel and equitable access to services managed effectively from the beginning

What user involvement will deliver

3. By involving patients we ***can get more bang for our buck***, by introducing cost-effective services which also improve patient experience

User involvement to get more ‘bang for our buck’

Case study: Implementing the overnight mastectomy model of care

- **The challenge:** To reduce mastectomy patients’ length of stay, save money, improve outcomes and patient experience
- **The user insight:** Working in partnership with NHS cancer networks and acute trusts across England, the NHS Improvement – Cancer Team tested the hypothesis that the streamlining of the breast surgical pathway could halve unnecessary lengths of stay, by managing patients’ expectations and changing clinical practice by making the system as efficient as possible with no loss of quality for the patient. Service users and potential service users were involved in re-designing the pathway from the beginning. Acute trusts engaged with users and local breast cancer charities, to identify the best method of implementation. There was continuing user evaluation including diaries and workshops and a post implementation audit of 2,000 patients.
- **The change:** The pathway includes a conversation with patients about the potential overnight model of stay from when the patients’ results are discussed and again at each interaction with professionals up until surgery. The patient is discharged with written and verbal information and community support is provided with visits for wound checks, support and drain removal. For more information go to www.improvement.nhs.uk
- **The result:**
 - Reduction in length of stay by 50%
 - Predicted savings of £1 million across a network population of 1.6 million people
 - Early indications – positive feedback from patients

What user involvement will deliver

4. By listening to the patient voice we can improve choice; ***enabling service users to articulate their values, needs and wants***, it is possible to make changes to services and offer real patient choice

User involvement to improve patient choice

Case study: Improving the oncology environment at the Churchill Hospital, Oxford

- **The challenge:** Issues in the flow, layout and operation of a cancer clinic
- **The user insight:** Paired service users undertook a 'patient-led audit' to identify what patients valued most. The feedback included:
 - Signage was poorly sited and unprofessional
 - The reception was a bottleneck and waiting time information was not located within the patient's sight
 - Long waits for patients, with many appointments running late
 - Calls were hard to hear
 - Information was badly organised; it was difficult to disaggregate support group material from information about cancer
- **The change:** As a result of the feedback, the clinic decided to develop:
 - New reception arrangements to improve the quality of the patient experience
 - New administrative changes to improve the scheduling of appointments
 - Plans to extend the clinic's available rooms for consultation and patient support
- **The result:** The service operated more efficiently and patient experience was improved. Changes such as these can be captured in future Service Level Agreements.

Making user involvement work for commissioning – top tips

- Involve patients from the outset
- Work together to decide what you want to achieve
- Make use of user involvement at each stage of the commissioning cycle
- Provide training support to enable users to understand the brief
- Ensure effective facilitation with local knowledge and credibility
- Undertake involvement at a sufficient scale to ensure a variety of perspectives are addressed
- Don't treat it as a 'tick box' to validate decisions
- Do evaluate the impact of user involvement

How to get started

- Engage your cancer network who already involve and support service users and who can take forward cancer specific user involvement on your behalf
- Speak to local user and patient support groups
- Seek help from NCAT and Macmillan Cancer Support